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# Comparing Quality of Dying and Death Perceived by Family Members and Nurses for Patients Dying in US and Dutch ICUs

Rik T. Gerritsen, MD; Matty Koopmans, RN, MSc; José G. M. Hofhuis, RN, PhD; J. Randall Curtis, MD, MPH; Hanne Irene Jensen, RN, PhD; Jan G. Zijlstra, MD, PhD; Ruth A. Engelberg, PhD; and Peter E. Spronk, MD, PhD

**BACKGROUND:** The Quality of Dying and Death (QODD) questionnaire is used as a self-reported measure to allow families and clinicians to assess patients' quality of dying and death. We evaluated end-of-life (EOL) experiences as measured by the QODD completed by families and nurses in the United States and the Netherlands to explore similarities and differences in these experiences and identify opportunities for improving EOL care.

**METHODS:** Questionnaire data were gathered from family members of patients dying in the ICU and nurses caring for these patients. In The Netherlands, data were gathered in three teaching hospitals, and data was gathered from 12 sites participating in a randomized trial in the United States. The QODD consists of 25 items and has been validated in the United States.

**RESULTS:** Data from 446 patients were analyzed (346 in the United States and 100 in the Netherlands). Dutch patients were older than those in the United States (72 + 10.2 years vs 65 + 16.0 years;  $P < .0025$ ). The family-assessed overall QODD score was the same in both countries: the Netherlands = median, 9; interquartile range (IQR), 8-10 and the United States = median, 8; IQR, 5-10. US family members rated the quality of two items higher than did the Netherlands families: "time spent with loved ones" and "time spent alone." Nurse-assessed QODD ratings varied: the single-item QODD summary score was significantly higher in the Netherlands (the Netherlands: median, 9; IQR, 8-10 vs the United States: median, 7; IQR, 5-8;  $P < .0025$ ), whereas the QODD total score was higher in the United States (the Netherlands: median, 6.9; IQR, 5.5-7.6 vs the United States: median, 7.1; IQR, 5.8-8.4;  $P = .014$ ), although it did not meet our criteria for statistical significance. Of the 22 nurse-assessed items, 10 were significantly different between the Netherlands and the United States, with eight having higher scores in the United States and 2 having higher scores in the Netherlands.

**CONCLUSIONS:** The QODD was rated similarly by family members in the United States and the Netherlands but varied when assessed by nurses. These differences may be due to organizational or cultural differences between the two countries or to expectations of respondents.

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**KEY WORDS:** end-of-life care; family satisfaction; ICU; quality of dying

**ABBREVIATIONS:** ANOVA = analysis of variance; EOL = end of life; IQR = interquartile range; QODD = Quality of Dying and Death Questionnaire; QODD-1 = single-item QODD

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Admission and treatment in the ICU has a major impact on the lives of both patients and their loved ones, and despite significant efforts by the clinical team, a considerable proportion of patients do not survive ICU care.<sup>1</sup> A patient's death affects both families and clinicians. For family members, poor end-of-life (EOL) care may lead to difficult bereavement and posttraumatic stress disorder, whereas clinicians caring for dying patients in the ICU may be at increased risk for burnout and moral distress.<sup>2-4</sup>

Previous studies have shown that family members are likely to have fewer psychological symptoms after the loss of a loved one in the ICU if the patient has received high-quality EOL care.<sup>5-7</sup> Interventions to improve quality of communication and quality of care have been associated with reduced psychological symptoms in some studies, although other studies suggest that such interventions have no effect or can actually increase psychological symptoms in some setting.<sup>8-12</sup> Given the heterogeneity of results with interventions to improve EOL care, further studies are needed to help guide these interventions, as well as the experiences of patients, family members, and clinicians. Furthermore, since family members' and clinicians' social and religious backgrounds, as well as the cultural and organizational context of care, influence both care and assessments of that care, understanding differences in care across different countries and organizations may provide insights into methods to improve care.<sup>13-15</sup>

In an effort to study the perceived quality of dying and death, the Quality of Dying and Death (QODD) questionnaire was developed through qualitative research and review of the literature, identifying several conceptual domains with acceptable reliability and validity.<sup>16-20</sup> An instrument like the QODD may be useful in detecting and understanding differences in care between settings. For example, QODD scores are higher

for patients dying at home compared with patients dying in the hospital.<sup>17</sup> It may also be useful for comparing differences between countries in which features of care, including organizational and cultural differences, may be important to consider. For instance, when comparing the United States and Europe, a higher proportion of patients in the United States die in an ICU setting than is true in Europe.<sup>15,21</sup> In addition, previous authors have speculated that EOL care in Europe is characterized by more paternalism and less focus on autonomy than in the United States.<sup>22,23</sup> The use of specialty palliative care teams in hospitals and ICUs also differs between Europe and the United States, which may influence EOL care in the ICU.<sup>23</sup> Finally, the ways in which EOL care is delivered and interpreted are influenced by cultural norms and practices.<sup>13,15</sup> Understanding the nature of differences in EOL care across different countries may provide an opportunity to identify targets for interventions to improve care in each country.

We previously showed that the family-assessed QODD score was high in several Dutch ICUs, suggesting a good quality of dying and death. Families assessed these experiences differently from ICU clinicians.<sup>24</sup> Others have also shown that families and ICU nurses provided significantly different assessments of the QODD.<sup>25</sup> Examination of international differences in ratings of the quality of dying and death for patients dying in the ICU, from the perspective of families and nurses, may provide insights into areas of relatively high- and low-quality care that suggest specific targets for improvement. In the current study, we hypothesized that assessments of the QODD would differ between the Netherlands and the United States for evaluations completed by both families and nurses. We also aimed to identify the specific experiences of the quality of dying and death, as measured by the individual QODD items, that were different in the Netherlands compared with the United States, where the QODD was originally developed.

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## Methods

### *Design and Setting*

The Netherlands sample included 100 consecutive patients dying in the ICU after an ICU stay of 48 h or longer. Data were collected from three nonacademic teaching hospitals over 8 months in 2012. All Dutch family members filled in the QODD assisted by a member of the study team during a telephone call 3 weeks after their loved one had died. Family members were also asked to return the filled-in questionnaire by regular mail. Nurses completed their questionnaire within 1 or 2 days after they finished the shift in which they cared for that patient. The method was described in detail previously.<sup>24</sup>

US data were collected as part of a multifaceted interdisciplinary quality-improvement intervention implemented as a randomized trial in 12 hospitals in Seattle, Washington<sup>26</sup> and as a before-and-after trial at one hospital.<sup>27</sup> Eligible patients were those who died in an ICU or within 30 h of transfer to another hospital location. In the US studies, questionnaires were provided to families by mail 4 to 6 weeks after a patient's death and were self-administered. Nurses caring for the identified patients at the time of death and during the previous shift were identified and provided a self-administered questionnaire within 72 h of the patient's death.<sup>26,27</sup> For the current study, only decedents with ICU lengths of stay  $\geq 48$  h were included in the analyses. Both studies were approved by their respective institutional review boards (R-TPO 706).

## Measures

The 25-item version of the validated QODD questionnaire was translated into Dutch by a native Dutch speaker and translated from Dutch to English by a native English speaker to confirm accuracy. The QODD includes questions assessing the quality of experiences that patients may have encountered at EOL. Each question has two parts: (1) "report items," in which the frequency of an experience/event is provided and (2) "rating items," in which the respondent evaluates the quality of the experience/event on an 11-point scale, ranging from 0 (terrible) to 10 (almost perfect). If families answered "I don't know" for the report items, they were directed to skip the rating item. For the 25-item nurse version, nurses were asked to rate the first 15 items and were asked for both reports and ratings for the remaining 10 items. Both the family and nurse versions have shown good internal consistency and validity.<sup>16-20,28-31</sup> For this study, we analyzed only the rating items and used 22 of the 25 items that were collected from both countries. Omitted items included "health-care costs," "overall health care," and "doctor's care last days." We also compared the individual QODD items across the two countries to understand the specific components of quality of dying that were different or similar in these settings.<sup>18</sup>

We used two summary measures: a single-item overall score and the summed total score on all items. The single-item QODD overall score (QODD-1) asks respondents the following question: "Overall, how would you rate the quality of your loved one's dying?" The QODD total score (QODD) is a summation of all available 0 to 10 ratings for

the 22 QODD items divided by the number of items completed, with higher scores indicating a higher quality of dying and death.

Patient demographics were derived from chart abstraction (both US and Netherlands samples) and death certificates (US sample only). Family characteristics and demographics were self-reported. Nurse characteristics were available only for the US sample and therefore were not included for analysis.

## Statistical Analyses

Using descriptive statistics, we analyzed the QODD's rating items and overall scores for each country, providing percentage of valid responses and means (SD) or median (interquartile range [IQR]) according to distribution. For differences in patient demographics,  $P < .05$  was considered statistically significant. To test for differences between countries, we examined individual QODD items and overall scores using both unadjusted and adjusted approaches. For unadjusted comparisons, we used the Mann-Whitney  $U$  test, a nonparametric statistic appropriate for the nonnormal distributions that characterized the QODD items and overall scores. When baseline differences in demographics between groups were identified with  $P < .20$ , multivariate regression analysis was performed, controlling for those differences. We used an analysis of variance (ANOVA) with backward stepwise method.

We present both unadjusted and adjusted analyses, because the unadjusted analyses provide evidence of the actual differences encountered in these ICUs in the Netherlands and the United States, whereas the adjusted analyses examine the differences that are more likely due to the country, adjusting for measured confounders. To control for the number of analytic comparisons, we adjusted the significance level ( $P < .0020$ ) using a Bonferroni correction for the number of tests.

In the US database, 20 nurses completed surveys for multiple patients. Clustered analysis revealed no effect on studied parameters of this clustering, and we therefore report the results of the unclustered analyses. Data were analyzed using PASW Statistics, version 18 (SPSS, Inc.).

## Results

### Sample

Four hundred forty-six patients with both family and nurse questionnaires (the Netherlands,  $n = 100$ ; the United States,  $n = 346$ ) were included in the study. The overall response rate was 89%. The two samples varied ( $P < .01$ ) on the following patient and family characteristics: (1) patient age, with patients from the Netherlands being significantly older ( $72 \pm 10.2$  years;  $P < .01$ ) than patients in the United States ( $65 \pm 16.0$  years); (2) family member age, with respondents from the Netherlands being older than family members from the United States (the Netherlands,  $61 \pm 13.7$  years vs United States,  $57 \pm 14.3$  years;  $P < .01$ ); and (3) length of patient-family relationship, with longer relationships in the Netherlands sample than in the US sample (the Netherlands,  $45 \pm 12.9$  years vs the United States,  $40 \pm 5.8$  years;  $P < .01$ ). The two samples did not

differ by the sex of patients (65% men), mean length of ICU stay (7 days), and the proportion of patients who were ventilated (the Netherlands, 97% vs United States, 91%) (Table 1).

### Single-Item Summary QODD Scores and Total QODD Scores

We examined two summary measures for family members, the QODD-1 and the average total score for all 22 items in this questionnaire (QODD-22). Both summary measures were similar when comparing assessments by family members from the Netherlands and those from the United States. The QODD-1 measures were the Netherlands: mean, 9; IQR, 8-10 and the United States: mean, 8; IQR, 5-10, and the 22-item QODD total scores were the Netherlands: mean, 6.6; IQR, 5.3-7.6 and the United States: mean, 6.6; IQR, 4.9-8.0 (Table 2).

**TABLE 1 ] Patient and Family Characteristics in Participating Centers**

Variable	All	The Netherlands	United States	P Value
No. of patients	446	100	346	
Age, mean (SD)	66 (15.2)	72 (10.2)	65 (16)	< .01
Male sex, No. (%)	286 (64.1)	66 (66.0)	220 (63.6)	.72
LOS in ICU Median (IQR), d	6 (3-13)	8 (3-16)	6 (3-12)	.228
LOS in hospital, median (IQR), d	9 (5-18)	11 (4-26)	9 (5-16)	.282
Living together, No. (%)	257 (59.6)	61 (68.5)	196 (56.6)	.09
Years known, mean (SD)	41 (15.4)	45.2 (12.9)	40 (15.8)	< .01
Family age, mean (SD)	57 (14.3)	61 (13.7)	57 (14.3)	< .01

Data presented as mean (SD), No. (%), or median (IQR) according to their distribution. Differences between groups were tested with the Student *t* test, the  $\chi^2$  test, or the Mann-Whitney *U* test, as appropriate. *P* < .05 considered statistically significant. LOS = length of stay.

We also examined these same two summary measures for nurse assessments. In contrast to the findings from the family-assessed QODD, the nurse-assessed QODD-1 score was significantly higher in the Netherlands (the Netherlands: mean, 9; IQR, 8-10 vs the United States: mean, 7; IQR, 5-8; *P* < .0020). However, the QODD total score based on 22 items was higher in the United States, although it did not achieve our definition of statistical significance (the Netherlands: mean, 6.9; IQR, 5.5-7.6 vs the United States: mean, 7.1; IQR, 5.8-8.4; *P* = .014).

#### *Family Members' Scores on Individual Items*

In unadjusted analyses of the 22 individual items, four items were significantly different (all *P* < .0020) between the United States and the Netherlands, with three higher in the United States: (1) spending time with family and friends (United States: 8.5 days [5-10 days] vs the Netherlands: 4.5 days [2-7 days]); (2) spending time alone (United States: 7 days [4-9 days] vs the Netherlands: 4 days [2-6] days); and (3) being touched and hugged by loved ones (United States: 9 days [8-10 days] vs the Netherlands: 8 days [8-9 days]). The item that was higher in the Netherlands was saying goodbye to loved ones (United States: 4 [0-8] vs the Netherlands: 5 [3-8]). In adjusted analyses, including those variables that differed significantly by country (ie, patient age, family age, length of relationship), the items "patient was touched and hugged by loved ones" and "saying goodbye to loved ones" were no longer significantly different (Table 2).

#### *Nurses' Scores on Individual QODD Items*

Of the 22 items, 12 were significantly different in unadjusted analysis between the Netherlands and the United States, with eight items rated higher in the United States and four items rated higher in the

Netherlands. Items that were rated as having significantly higher quality for nurses in the United States included ratings about the patient having control, feeding himself/herself, laughing or smiling, spending time alone and with family, saying goodbye, and the presence of a spiritual advisor or service (Table 3). Ratings that were significantly higher when rated by the nurses in the Netherlands included having had discussions about EOL wishes with a physician, being on a ventilator, having someone present at the moment of death, and the QODD-1 (*P* < .0020). In the adjusted analyses in which we controlled for patient age, the items "discussed EOL wishes with doctor" and "experience of mechanical ventilation" were no longer significantly different. The significance of the other 10 items remained.

## **Discussion**

To the best of our knowledge, this is the first study reporting on the similarities and differences between family and nurse ratings of the quality of dying and death for patients dying in ICUs in the Netherlands and the United States. We examined responses from families of 446 patients in the ICU and found that despite organizational, cultural, and social differences between these countries, family assessments were similar across the two countries. Only three of the 22 answered items were significantly different between countries, and overall ratings, whether assessed with a single rating item or a total score, did not vary. This similarity persisted independent of whether analyses were adjusted for differences in patient and family demographics that have been linked to differing QODD ratings. Importantly, family ratings of experiences that were identified as critically important to a good death, like good symptom control and the delivery of timely and

**TABLE 2 ] Family Responses of Patients Who Stayed  $\geq$  48 h in the ICU**

Questions (% Valid Responses)	All (N = 446) Median [IQR]	Netherlands (n = 100) Median [IQR] (% Valid Responses)	United States (n = 346) Median [IQR] (% Valid Responses)	Unadjusted P Value <sup>a</sup>	Adjusted P Value <sup>b</sup>
Had control of pain (81)	8 [6-9]	8 [5.75-8.25] (87)	8 [6-9] (89)	.813	
Had control over what was going on around him/her (81)	7 [3-9]	7 [4.5-8] (87)	7 [3-9] (88)	.956	
Was able to feed himself/herself (78)	5 [2-8]	6 [3-8] (74)	5 [1-9] (82)	.535	
Breathing comfortably (84)	5 [2-8]	6 [4-7] (84)	5 [1-8] (89)	.373	
Felt at peace with dying (52)	7 [3-9]	7 [5-8] (86)	7 [3-9] (57)	.919	
Was unafraid of dying (50)	7 [4-9]	8 [5-9] (88)	7 [3-9] (56)	.621	
Laughed and smiled (77)	5 [1-7]	5 [2-7] (79)	4 [1-7.5] (80)	.178	
Maintained dignity and self-respect (84)	7 [3-9]	7 [3-8.25] (89)	8 [3-9] (80)	.243	
Spent time with family (77)	8 [5-10]	4.5 [2-7] (82)	8.5 [5-10] (88)	<b>&lt; .001</b>	<b>&lt; .001</b>
Bad feelings spoken out (60)	5 [2-9]	5 [2-7.5] (73)	5 [2-9] (61)	.074	
Spent time alone (78)	6 [3-9]	4 [2-6] (83)	7 [4-9] (85)	<b>&lt; .001</b>	<b>&lt; .001</b>
Was touched and hugged by loved ones (89)	9 [8-10]	8 [8-9] (88)	9 [8-10] (89)	.010	.650
Said goodbye to loved ones (78)	5 [1-8]	5 [3-8] (85)	4 [0-8] (77)	.007	.030
Had visits from spiritual advisor (72) or	8 [5-10]	8 [5.5-9] (68)	8 [5-10] (81)	.086	
Spiritual service or ceremony before death (68)	8 [5-10]	8 [6.5-9] (64)	8 [5-10] (75)	.173	
Had funeral arrangements in order (83)	7 [4-9]	8 [6-9] (75)	6 [3-9] (85)	.078	
Discussed EOL wishes with physician (75)	7 [4-9]	[5.5-8.5] (74)	6 [4-9] (78)	.941	
Experience of mechanical ventilation as an aspect of dying (88)	7 [2-9]	7 [3-8] (87)	6 [2-9] (88)	.799	
Experience of dialysis (54)	8 [5-10]	8 [5-9] (56)	7 [5-10] (54)	.983	

(Continued)



TABLE 2 ] (Continued)

Questions (% Valid Responses)	All (N = 446) Median [IQR]	Netherlands (n = 100) Median [IQR] (% Valid Responses)	United States (n = 346) Median [IQR] (% Valid Responses)	Unadjusted P Value <sup>a</sup>	Adjusted P Value <sup>b</sup>
Was anyone present at the moment of death? (86)	9 [8-10]	9 [8-10] (85)	9 [7-10] (86)	.134	
State before death (83)	8 [5-10]	8 [5-9] (87)	8 [4-10] (82)		
Single item QODD-1 (93)	8 [6-9]	9 [8-10] (89)	8 [5-10] (95)	.309	
Total QODD <sup>c</sup>	6.6 [4.9-8.0]	6.6 [5.3-7.6]	6.6 [4.9-8.0]	.390	

Differences tested with the Mann-Whitney *U* test. *P* for significance, < .0020. Boldface indicates significant values. ANOVA = analysis of variance; EOL = end of life; QODD = Quality of Death and Dying Questionnaire; QODD-1 = single-item QODD.

<sup>a</sup>Univariate analysis.

<sup>b</sup>Multivariate regression analysis (ANOVA, backward method) including the following confounders: patient age, family age, length of relationship.

<sup>c</sup>Total QODD is numerical sum of scores of all questions administered in both countries divided by the number of questions answered.

accurate information,<sup>32,33</sup> did not differ between the two countries. There was a difference between family ratings of the quality of “patient time spent with his/her loved ones,” which was rated higher by families in the United States. This is an important finding, since previous studies have suggested the importance of this item when evaluating EOL care.<sup>32,33</sup> This may be an area in which the Dutch ICUs have room for improvement by increasing or facilitating family presence, such as with more open visiting policies.<sup>34</sup> Conversely, the families from the Netherlands scored higher on the item “saying goodbye to loved ones,” suggesting this might be a reflection of a cultural difference but may also be a target for interventions in the United States by stimulating family members to express their feelings.

We used an instrument validated in the United States to measure quality of dying in the Netherlands. The similarities between the answers of the family members in the United States and those in the Netherlands suggests the applicability of the instrument in the Netherlands, although we have previously shown that Dutch family members judged the questionnaire difficult and a few items irrelevant. This finding has led to an initiative to adapt the questionnaire for European use. A joint Danish-Dutch project called the “European Quality Questionnaire” is currently developing and validating such an adaptation of the QODD as well as the Family Satisfaction in the Intensive Care Unit questionnaire.<sup>24</sup>

In this study, we also examined nurse ratings of the quality of dying and death for patients. In contrast to family assessments, nurse scores varied significantly between the two countries. To our knowledge, few data are available assessing nurses’ experiences in different

countries, except for a study of differences in the quality of nurse handover.<sup>35</sup> The current differences in QODD ratings may be associated with organizational differences. For example, in the Netherlands, an intensivist is always present in the ICU, which might help address symptoms earlier. Indeed, higher symptom control ratings may reflect this responsiveness.<sup>33</sup> Additionally, nurses in Dutch ICUs may play a more active role in the decision-making process including EOL decisions.<sup>36</sup> A prior report from Sweden found that nurses’ experiences of inappropriate care, a known stressor for nursing staff, may occur less often with this direct involvement of nursing staff in decision-making.<sup>37,38</sup> There may also be important differences in expectations of nurses in different countries that may influence ratings.<sup>39</sup> Finally, the QODD differences may reflect a cultural difference between the two countries in either the care delivered or the expectations of nurses about the care delivered.<sup>40</sup>

We report two approaches to providing an overall rating of the quality of dying, a single-item summary score and a total score using the average of 22 items. Interestingly, these two approaches yielded different summaries of the differences in nurse ratings between the Netherlands and the United States. There may be important limitations in using an average score for multiple items if those items do not have a unidimensional domain structure.<sup>16,39</sup> The single-item rating may provide a more reliable summary rating, but further work is needed before this measure is ready for use as a primary outcome of intervention studies.<sup>16</sup>

Our study has several limitations. First, data collection was not specifically planned for the purpose of

**TABLE 3 ] Nurses' Responses for Patients Who Stayed  $\geq$  48 h in the ICU**

Questions (% Valid Responses)	All (N = 446) Median [IQR]	Netherlands (n = 100) Median [IQR] (% Valid Responses)	United States (n = 346) Median [IQR] (% Valid Responses)	Unadjusted P Value <sup>a</sup>	Adjusted P Value <sup>b</sup>
Had control of pain (86)	8 [7-9]	8 [6-9] (73)	8 [7-9] (90)	.535	
Had control over what was going on around him/her (69)	5 [1-7]	1 [0.5-8] (63)	5 [2-7.5] (71)	<b>&lt; .001</b>	<b>&lt; .001</b>
Was able to feed himself/herself (59)	2 [0-5]	0 [0-0] (69)	4 [0-5] (57)	<b>&lt; .001</b>	<b>&lt; .001</b>
Breathing comfortably (87)	7 [5-9]	6 [2.5-7.5] (71)	7 [4-9] (92)	.301	
Felt at peace with dying (51)	8 [5-9]	9 [5-9] (39)	8 [36-9] (55)	.706	
Was unafraid of dying (41)	8 [5-9]	7 [3.5-8] (33)	8 [5-9] (43)	.015	.020
Laughed and smiled (53)	3 [0-5]	0 [0-5.5] (50)	4 [1-6] (54)	<b>&lt; .001</b>	<b>&lt; .001</b>
Maintained dignity and self-respect (74)	8 [5-9]	8 [5-8] (53)	8 [5-9] (80)	.623	
Spent time with family (78)	9 [7-10]	6 [0-8] (39)	9 [7-10] (90)	<b>&lt; .001</b>	<b>&lt; .001</b>
Bad feelings spoken out (30)	2 [0-5]	0 [0-5] (34)	3 [0-5] (28)	.009	.020
Spent time alone (61)	7 [4-9]	1.5 [0-5] (30)	7.5 [5-9] (69)	<b>&lt; .001</b>	<b>&lt; .001</b>
Was touched and hugged by loved ones (91)	9 [8-10]	9 [8-10] (88)	9 [8-10] (91)	.315	
Said goodbye to loved ones (60)	5 [0.25-8]	0.5 [0-7] (52)	5 [1-9] (62)	<b>.001</b>	<b>.001</b>
Had visits from spiritual advisor (67) or	8 [4-10]	0 [0-8] (71)	8 [6-10] (65)	<b>&lt; .001</b>	<b>&lt; .001</b>
Spiritual service or ceremony before death (59)	7 [1-10]	0 [0-7] (80)	8 [5-10] (54)	<b>&lt; .001</b>	<b>&lt; .001</b>
Discussed EOL wishes with physician (47)	6 [3.5-9]	8 [5-10] (41)	5.5 [3-9] (49)	<b>.002</b>	.009
Experience of mechanical ventilation as an aspect of dying (85)	7 [5-9]	8 [6-9.75] (80)	7 [5-8] (87)	<b>.002</b>	.010
Patient kept alive too long, yes No. (%) <sup>c</sup>	77 (24)	64 (30)	13 (13)	<b>&lt; .001</b>	.021
Experience of dialysis (40)	8 [5-9]	9 [7-10] (43)	8 [5-9] (39)	.022	.110
Right amount of sedation (95)	9 [7-9]	9 [8-10] (81)	8 [7-9] (98)	.240	
Was anyone present at the moment of death? (80)	9 [8-10]	10 [9-10] (95)	9 [8-10] (76)	<b>.001</b>	<b>.001</b>

*(Continued)*



TABLE 3 ] (Continued)

Questions (% Valid Responses)	All (N = 446) Median [IQR]	Netherlands (n = 100) Median [IQR] (% Valid Responses)	United States (n = 346) Median [IQR] (% Valid Responses)	Unadjusted P Value <sup>a</sup>	Adjusted P Value <sup>b</sup>
State before death (96)	9 [8-10]	9 [8-10] (94)	9 [7-10] (98)	.004	.040
QODD-1 (99)	7 [6-9]	9 [8-10] (99)	7 [5-8] (99)	<b>&lt; .001</b>	<b>&lt; .001</b>
Care from health professional (98)	9 [8-9]	9 [8-10] (99)	9 [8-9] (98)	.110	
Care from doctors (98)	9 [8-9]	9 [8-10] (99)	9 [7-9] (98)	.200	
Total QODD <sup>d</sup>	6.9 [5.7-8.3]	6.5 [5.7-8.3]	7.1 [5.8-8.4]	.013	.014

Differences tested by Pearson  $\chi^2$  test or Mann-Whitney *U* test as applicable. *P* for significance, < .0020. Boldface indicates significant values. See Table 2 legend for expansion of abbreviations.

<sup>a</sup>Univariate analysis.

<sup>b</sup>Multivariate regression analysis (ANOVA, stepwise backward method) including the following confounder: patient age.

<sup>c</sup>Kept alive too long is a yes/no question, so median (IQR) cannot be reported.

<sup>d</sup>Total QODD is numerical sum of scores of all questions administered in both countries divided by the number of questions answered.

comparing the quality of dying and death between these two countries, and therefore the data were not collected in identical ways. For example, family members from the United States independently filled out a mailed questionnaire without assistance, whereas family members in the Netherlands were offered assistance by telephone when filling in their questionnaires. The questions asked were the same, but some research suggests that response mode, particularly regarding sensitive topics, may alter response patterns.<sup>41,42</sup> Despite these cautions, we think a comparison between the data from the United States and that from the Netherlands is feasible, since our sample criteria and measures were the same. Second, in the United States sample, nurses graded the quality of care for more than a single patient. However, clustered analysis showed that findings were robust. Third, we did not look at several factors that may have influenced QODD scores, such as admission from the ED vs the acute-care hospital<sup>43</sup> and the attending physician's specialty.<sup>44</sup> These factors may have influenced the QODD, and we cannot rule out that these factors may have played a role in our findings. Fourth, differences in the timing of administering the questionnaire to families—3 weeks in the Netherlands and 4 to 6 weeks in the United States—and to a lesser extent, a 1-day difference in time given to nurses, might have biased our results. It was shown previously that timing of interviewing bereaved people affects the results obtained.<sup>42</sup> However, a randomized trial suggests no

difference between 2 and 6 weeks, and the similarities between family ratings in the Netherlands and the United States make this less of a concern.<sup>45</sup> Fifth, the QODD has been validated in the United States but not in the Netherlands, so some of the differences we found may reflect differences in validity of the tool in different cultures, as well as the different EOL care, such as availability of palliative care consultation in ICUs, between the United States and the Netherlands. An European initiative to establish the use of palliative care consultation in ICUs is starting this year. Finally, some of the items had a high number of missing data, which introduces the risk of nonresponder bias.<sup>24</sup>

In conclusion, the quality of dying and death as perceived by families of patients dying in ICUs in the Netherlands and the United States is similar and seems to be rated relatively high. In contrast, nurses from these two countries provided significantly different ratings, which might be attributed to organizational or cultural differences between countries and may also reflect differences in perceptions and expectations. Further studies are needed to understand differences between countries in ratings of quality of EOL care. In the meantime, this study identifies some potential targets to improve EOL care in both the United States and the Netherlands. These targets could be used to explore and evaluate interventions to improve EOL care.

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